

Addressing End-of-Life Issues

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We are all going to die; I think we would all prefer to die with dignity.

Not too long ago, the country watched the anguish of family members of Terri Schiavo torn apart over prolonging her life or allowing her death. Their very public suffering was certainly not what any of us would want our relatives to face, nor would we want to find ourselves a grieving family member in a public spectacle such as that which surrounded this woman's death.

The courts are the last place such issues should be decided. Ideally, they should be decided by each individual for him- or herself. The right of competent adult Americans to refuse unwanted medical intervention is well established. The Patient Self-Determination Act of 1990 clearly put forth the right of every patient's control over end-of-life care, assuming that the choices would be fully informed.¹

One hopes that we, as health care providers, are personally prepared and

have discussed our own end-of-life preferences with our families and significant others. That way, should we become incapacitated, our wishes will be clear and not up for debate. Our patients should do the same, but many do not. A 1999 study of members of a health maintenance organization who were 65 years or older reported only one-third had advance directives.²

What is our role, as health care providers, in helping our patients prepare for such eventualities?

Many of us are being bombarded by patients' inquiries regarding "living wills," "advance directives," or "health proxies" in the aftermath of the Schiavo case. Those who are not should initiate conversations about these issues with patients. The goal is for patients to make their wishes known before they may be in an incapacitated state. In the 1999 study mentioned above, only 15% of patients reported having been asked about their advance care preferences by a health care provider, and those who had been asked were three times more likely to establish such directives.² For patients with chronic diseases including diabetes, the seriousness of their disease should be discussed. Diabetic patients should be aware that complications, particularly if their disease has not been optimally treated, can lead to premature death, especially from cardiovascular disease.

Even younger patients should think about these issues. Mrs. Schiavo was only in her 20s when she had the cardiac arrest that left her in a permanent vegetative state from cerebral hypoxia and ischemia. It is appropriate to discuss this topic with every adult patient, not just the elderly or sick. Quality of life—not death—should be the focus of the conversation. Elderly individuals are more concerned with functional outcome than with the medical interventions used to achieve those outcomes.³

Some physicians report that the reason that they do not discuss these issues

with their patients is that they fear the patients will be uncomfortable talking about their own deaths.⁴ However, the contrary may be true. One study⁴ found that 93% of outpatients and 89% of the general public were interested in discussing advance directives.

Some patients may need help making such decisions, so returning to these issues at subsequent visits may allow them to arrive at decisions over time. Some patients will need guidance. A 2000 study at two university-affiliated clinics in the western United States⁵ suggested that a significant proportion of patients misunderstand their options for end-of-life care. This same study also found that patients were more likely to be able to come to conclusions about their own care by exploring previous experiences with a loved one's illness or death (87% of the study population had such experiences).

When decisions are reached, patients' choices should be documented and revisited periodically. Patients should designate a health proxy and discuss the specifics regarding end-of-life care with their proxy. This should include exactly what the patients do and do not want done and under what circumstances.

For health care providers who feel uncomfortable or inadequate about discussing end-of-life topics with patients—and many do—there are resources available to help in developing

such skills. The American Medical Association has a training program called Education for Physicians on End-of-Life Care, which teaches communication skills relevant to a spectrum of end-of-life issues.⁶

Clarifying patients' preferences about the care provided to them when they are incapacitated is part of the responsibility that we, as health care providers, assume in caring for patients. Would that no other family has to experience the pain and anguish felt by Terri Schiavo's relatives, whether publicly or in private, of struggling with questions of what their loved one would have wanted at the end of life.

REFERENCES

- ¹American Bar Association: Patient Self-Determination Act of 1990 [article online]. Available from www.abanet.org/publiced/practical/patient/_self_determination_act.html
- ²Gordon NP, Shade SB: Advance directives are more likely among seniors asked about end-of-life preferences. *Arch Intern Med* 159:701–704, 1999
- ³Rosenfeld KE, Wenger NS, Kagawa-Singer M: End-of-life decision making: a qualitative study of elderly individuals. *J Gen Intern Med* 15:620–625, 2000
- ⁴Emanuel LL, Barry MJ, Stoeckle JD, Ettelson LM, Emanuel EJ: Advance directives for medical care: a case for greater use. *N Engl J Med* 324:889–895, 1991
- ⁵Silveira MJ, DiPiero A, Gerrity MS, Feudtner C: Patients' knowledge of options at the end of life. *JAMA* 284:2483–2488, 2000
- ⁶Emanuel LL, von Gunten CF, Ferris FD: *The Education for Physicians on End-of-Life Care (EPEC) Curriculum*. Chicago, Ill., American Medical Association, 1999